

Family Connections Center



Saturday, May 4th, 2019
Fort Phoenix State Reservation
Fairhaven, MA

We encourage people of all abilities to participate in this fund/fundraiser

Friendly dogs are also welcomed to join us!

The first 125 registered adults receive an event T-Shirt and all registered children (under 12) also receive an event T-Shirt

Register at www.nemasketgroup.org

The Arc of Massachusetts FY'2020 Budget Narrative Governor Baker's Proposal

The Arc of Massachusetts profoundly thanks Governor Baker for his support of people with disabilities and their families in his new FY'2020 budget proposal starting July 1, 2019. The governor has added significant funding in the areas of housing, employment, transportation, and adult services for those with intellectual and developmental disabilities (I/DD), including autism.

- 1) The new formula for Turning 22 is sticking. Initiated by Gov. Baker and Secretary Sudders, this program will serve 891 people with ID and 267 people with DD. 245 persons are expected to receive residential services from this class. In this account 1,158 people will begin their transition to adult services in FY'2020 starting on July 1, 2019. Future funding for this year's 1,073 graduates (ending June 30, 2019), is reflected in the accounts below.
- 2) Residential account received significant maintenance funding with \$36 million for Turning 22 annualization of 238 persons and the remainder (approximately \$50 mil) to address increasing needs of people presently served as well as addressing deteriorating housing.
- 3) Day and employment services received maintenance funds of \$22 million with several hundred people (895 projected) needing day supports. This amount should cover annualization but will not be enough for other maintenance needs despite its significance. More is requested.
- 4) Family Support received \$1.5 million in annualization of funds for those individuals with I/DD who turned 22 years old last year. We hope to gain \$3.4 million more for those waiting.
- 5) DESE-DDS program (Department of Elementary and Secondary Education partnership program with Department of Developmental Services) is a great surprise with 61% hike of \$4 million to help address the 778 new applications to keep children with families. The program now serves 500 families. It offers skill building, specialized therapies, increased independence, and social integration in the community. Youth involved in this program often experience more success in school settings.
- 6) The Autism Adult (Omnibus) increase of \$6.9 mil addresses 192 people who graduated last year through the T22 class. This funding continues services from last year. No funding is available for individuals on the waiting list who turned 22 prior to FY'15.
- 7) The Transportation increase of \$4.4 mil will assist with T22 annualization, but we do face some significant problems in this area partly due to the cost of transportation in rural and suburban areas and the need for better coordination.
- 8) State Services including State Operated Community Residential, DDS Admin and Serv. Coord and Facilities all grew to meet collective bargaining agreements – no further staff are included in the increases for those line items.
- 9) Aging with DD is at \$100,000 with a budget reduction of \$30,000 from last year based on the FY 2018 spending. These funds target those with dementia or related conditions.

We want to continue this Administration's forward thinking as significant state investments are needed to help solve the current workforce shortage crisis of direct care staff for families and people with disabilities. This shortage threatens the safety of people with I/DD and their ability to live, work, and contribute in their community.

To learn more, visit www.arcmass.org, follow [@TheArcofMass](https://twitter.com/TheArcofMass) on Twitter, or [join our Facebook community](#).

Food for *Thought*

Dream Without Limits!

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

The American Dream. It's what motivates us to believe we can achieve our fondest hopes. Collectively, we may not share the same definition of The American Dream; to some it's a house with a picket fence, to others it's a college education or owning your own business. What we *do* seem to collectively hold dear is the *idea* that we can pursue and achieve whatever is important to us.

Unfortunately, this doesn't always apply to individuals who have been diagnosed with disabilities. The dream that parents hold for their precious baby often evaporate in the wake of a disability diagnosis and a physician's dismal prognosis.

The carnage may continue throughout a person's life. Special services, interventions, and therapies can be effective dream-smashers. Instead of supporting the heartfelt hopes of an individual, they generally focus on addressing a person's "problems" (as determined by others). This is enough to erode a person's self-esteem and plant the seeds of hopelessness. Moreover, the time spent in these activities reduces the amount of time one can spend pursuing one's dreams.

Special ed preschools, segregated special ed rooms in public schools, group homes, sheltered work settings, and other unnatural environments can also successfully destroy dreams. In these environments, "success" is measured by a person meeting goals that have been written by others, instead of by the achievement of personal hopes and dreams. In the process, the freedom to explore – and to succeed and fail – is replaced by regimentation and routine. By the time children with disabilities have grown into adults, many have lost the will to dream. The fading glimmer of hope is extinguished. (When service providers lament

that it's hard to find a job for a person with a disability because he's "not interesting in anything," they might consider looking at his past. If he wasn't permitted to dream as a child, he may need lots of encouragement to dream as an adult.)

Interventions and unnatural environments aren't the only dream-crushers, however. The words and actions of parents, educators, service providers, doctors, and others can devastate a person's hopes and dreams, and so can the *absence* of words and actions. What we *don't* do or say about dreams can contribute to a person's believe that he *shouldn't* dream.

Hopes and dreams are the daily duel that energize people who *don't* have disabilities.

Some dreams are realized, others aren't and still others change. Again, the final outcome isn't as important as the *idea* that a person can influence her present and future through her hopes and dreams. If we expect individuals with disabilities

to succeed, they must be able to dream. Each of us has an important role to play, and there's a cardinal rule that can guide us: help a person dream, but if you can't help, *at least do no harm*.

Brianna, 14-year-old who did not have a disability, loved being with young children and decided she wanted to be a pediatrician. Her mom didn't say, "You can't be a doctor – you hate needles and blood!" She didn't want to dampen her daughter's enthusiasm, and felt Brianna might decide to tolerate needles and blood in order to achieve her goal. So she suggested Brianna become a hospital junior volunteer to see if she like the medical environment. After a year of mostly enjoyable experiences, Brianna decided the medical field wasn't for her! She felt a little lost then, not knowing what type of career she should pursue, and she wondered if the year was a wasted

I DREAM,
THEREFORE I BECOME.

CHERYL GROSSMAN

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effort. But her parents helped her recall the interesting experiences, which had contributed to her growing maturity. Further, they helped her see that knowing what she didn't want to do was valuable knowledge.

Dreaming inspires curiosity – a willingness to try new things. Poking a hole in someone's dreams can diminish this curiosity. Do we have the right to do this? On the flip side, telling someone she can't do something may motivate her to pursue it just to prove the naysayer wrong. How many have traveled such a path, doing something they don't really want to do, and making themselves miserable, in order to save face?

Jonathan, a teenager with a disability, has dreamed of many careers since he was a young child, including being a firefighter and a basketball player. His parents never said, "you're not being *realistic!* You can't be those things – you have a disability and use a wheelchair." Instead, they responded with the same words they said to their other children: "You can grow up to be anything." They knew *all children* need their parents to believe in them so they can believe in themselves. They also knew children change their minds countless times! How many adults are doing the jobs they dreamed of as children? As children, we don't know about the countless career opportunities that may be available, *and* our interests change as we grow. And once a career is begun, how many people stay there for thirty years? Many have enjoyed multiple careers in different fields!

Jonathan's parents also trusted in their children's ability to learn what they're capable of and what they aren't. In Jonathan's case, they knew that (1) he would probably figure out fighting fires and playing basketball weren't the best choices or (2) if, as an adult, he still desired to pursue a career in a field that's considered "off-limits" to a person using a wheelchair, he would figure out how to make it work.

So, encouraging a person to dream requires trust. When we trust in a person, we also send the message that we believe in him, which enables him to believe in himself. We're also sending the message that we have great

expectations, and this is a sharp contrast to the low expectations that many people have routinely assigned to individuals with disabilities. Is there any greater hurt we can inflict on a person than to have no hopes and expectations for him? The trust and belief of others – especially parents – are pillars of strength that can support a person throughout his lifetime, even during difficult times when he may temporarily lose trust in himself.

Trusting can come only when we rid ourselves of the arrogant belief that we "know" what a person can/can't do. *We don't know* – we can only guess. Even an informed opinion is just that; *one person's opinion*. Do we dare let our opinions crush the life out of another's hopes and dreams?

When a person with a disability has a dream that seems unachievable, we can learn more about what the dream really means, instead of dismissing it as "unrealistic." The late Jerry Kiracofe shared an experience that illustrated this important lesson.

Jerry was helping a man with a disability find his place in the community – a job and home – so he could get out of an institution. Steve's dream was to be an astronaut. In his gentle fashion, Jerry let Steve know that he didn't have the qualifications to be an astronaut, then asked what other jobs he might like. "Astronaut," Steve replied, and he wouldn't budge from his position.

Jerry realized he needed to discover what about being an astronaut was so appealing. Since Steve had grown up in the institution, his only exposure to space travel was watching it on TV news. After getting to know Steve better, Jerry was able to find a job that fulfilled Jerry's hope:

working at the Smithsonian Air and Space Museum as a custodian. Steve didn't really want to be an astronaut, he wanted to *wear* a snappy uniform (like an astronaut) and be around airplanes and spacecraft. Only by really listening to Steve (and not pooh-poohing his idea) was Jerry able to help him achieve his dream.

Joan, a wise mother of a teenager with a disability, helped her son's dream come true by listening and by removing barriers to her son's

Reality can destroy the dream; why shouldn't the dream destroy reality?

George Moore

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success. At 17, Jim languished in the special ed room at school, hating every minute of it and hating himself, too. Joan said enough was enough; she was tired of her son being hurt by the low expectations of educators. Jim quit school, Joan helped him prepare for the GED, and they began thinking about jobs.

Jim – like lots of us at that age – didn't know *exactly* what he wanted to do, but he pictured himself driving a truck and wearing a uniform. Mother and son explored their community and soon, Jim was working as an apprentice at a pest control firm. With his eagerness, determination, and newfound self-esteem, he quickly moved beyond apprenticeship. Not only did he get to wear a uniform and drive a truck, it was a cool truck with a bug on top (for a pest extermination company)!

Do we have the *right* to question the validity of another's dreams? Wearing a uniform may meet someone's need to be "part of something," perhaps it's desired as an expression of authority, or it can mean anything else. Who knows? Dreams are precious possessions; *their value can only be assessed by the dreamer.*

To support my son's dream of being an actor, we enrolled him in drama classes. For two years, he pursued this dream, vid drama classes and performing in several plays. Then a new dream took him on a different path. He now wants to be a writer, specifically a movie critic (he wants Roger Ebert's job). One-finger typing has served him to this point, but his dream may be more achievable with a notebook computer and voice-to-text software we recently purchased for him. Does this person with a disability in your life have the assistive technology, accommodations, supports, *and* the opportunities and encouragement she needs to enable her pursue her dreams?

Methods to encourage dreaming and support a person's dreams are infinite; a few examples have described. Generally, each of us

can critically examine our past actions and do whatever it takes to improve our efforts. Parents can *choose* to restore the same dreams that grew in their hearts before their child was diagnosed. Educators, service providers, and others can choose to soften the hard shell of "professionalism" (which often equates to cynicism, pessimism, and "delivering bad news"), and reacquire the capacity to inspire hope.

We can also initiate – on a regular basis – conversation about hopes and dreams with a person we care about. Dreams come in all shapes and sizes: seeing the latest movie, having a birthday party, going on vacation, pursuing a particular career, or anything else! And respecting those dreams – whether we agree with them or not – is crucial. When we can't share honest enthusiasm, we can use a middle-

of-the-road approach by saying, "That sounds really interesting," or something similar. Supporting someone's dream doesn't mean we must agree 100 percent; it does mean, however, that we don't diminish the importance of the dream – and by extension, the importance of the *dreamer* – by dishing out insults, disbelief, or any other negative reactions.

With our misguided assumptions and beliefs about the abilities and potential of people

who have disabilities, we have unintentionally limited a person's opportunities to dream. We can get beyond these self-imposed barriers if we suspend disbelief in the traditional disability paradigms; "problems," "not ready," "needs to be fixed," and more.

Basking in the joy of anticipation that comes with dreaming, working hard to achieve a dream, and replacing old dreams with new ones are integral parts of life for *everyone*. What kind of life would have today if you hadn't experiences all of these? The need to dream is a universal human trait that we can no longer deny to others on the basis of disability.

Stories were full of hearts being broken by love, but what really broke a heart was taking away its dream, whatever the dream might be.

Pearl S. Buck

Upcoming *Events*



AFAM's 15th Annual Autism Advocacy Day

Thursday, April 11 9:30 - 11:30AM
Great Hall, Massachusetts State House

Advocates for Autism of Massachusetts (AFAM) will be hosting their 15th Annual Autism Advocacy Day on Thursday, April 11. Representative Kay Khan will be recognized as Legislator of the Year and Cheryl Ryan Chan will speak on Nicky's Law. Emcees are Heather Hegedus of Fox25 news and Gyasi Burks-Abbott. If you have any questions, contact Judy Zacek at 781-891-6270, Ext 102, or visit www.afamaction.org.

Medical Safeguarding Protecting the Health and Lives of Vulnerable People



This workshop is based on the work of Dr. W. Wolfensberger of the Syracuse University Training Institute, as well as the practical experiences of clinicians, family members, and advocates. The workshop explores the unpleasant and paradoxical reality that anyone who is hospitalized is exposed to grave dangers which jeopardize that person's health and safety, sometimes to the point of affecting whether they live or die. The workshop will offer practical information and examples on necessary guidelines and measures for protecting people in the hospital.

Tuesday, April 23, 2019
9:00-3:00
Rosebrook Conference Center
50 Rosebrook Place
Wareham, MA 02571

To register, visit: <http://nemasketgroup.org/medical-safeguarding-workshop-april-23-2019/>

** Nursing CEU's will be available**

Department of Developmental Services

DDS 101 Training

What you should you know about DDS as the transition from high school to life after high school approaches?

This free workshop will focus on the following topics:

ELIGIBILITY

How do I become eligible for DDS Services?

AREA OFFICE

What is the role of the DDS Area office?

FAMILY SUPPORT

What can Family Support provide to my family, and what are the limitations?

SELF-DIRECTION

*What are Self-Directed Services?
How do they differ from Traditional Services?*

AUTISM SERVICES

What support is available to my family member with autism, and how do we access it?

When: April 18, 2019, 5:30PM-7:30PM

Where: DDS Southeast Regional Office
151 Campanelli Drive, Middleboro Ma 02346

RSVP BY APRIL 12th

Contact Ed Wilson, Southeast Regional Manager Self-Directed Services
Edward.B.Wilson@state.ma.us or 508 866 8864

Strangers in the House: The Dilemma of Living with In-Home Services



Families and individuals who receive in-home support services typically face a major problem when trying to maintain the integrity of their private home and family lives despite the inescapable disruptions that come with service-provider presence in the home, especially when the support is very extensive or involves many different workers. *This difficulty exists even when families and individuals have good personal relationships with their in-home support personnel, and even when they are adequately sensitive to the issues at stake.* But when good personal relationships and sensitivity are absent, the situation can become intolerable.

This one-day presentation explores the dilemma of living with in-home services. It offers insights, practical advice and strategies for managing the issues involved, and invites participants' reflections on the types of mind-sets that might improve or worsen this dilemma.

When: **Monday, April 29, 2019**
8:30am Registration
9:00am – 4:00pm Workshop
Lunch will be provided

Where: **BayCoast Bank** – Conference Center
330 Swansea Mall Drive
Swansea, MA

To register, contact Amy Cornell
at *The Nemasket Group* 508-999-4436 or email AmyCornell@NemasketGroup.org

Intended Audience:

- Individuals, family members and care-givers who currently use, or in the future may use, in-home supports
- representatives of support-providing services, including: visiting nurses, hospice workers, home health aides, respite workers, personal care assistants, direct support professionals and supervisors

About the Presenter:

This workshop was developed, and will be presented, by Jo Massarelli, of the Social Role Valorization Implementation Project in Worcester, Massachusetts. Professionally, Jo has long been involved with families and individuals who receive in-home supports, as well as representatives of support-providing services. Personally, she has been a caregiver for family members and neighbors who also have had in-home services.

Sponsored by:
DDS Regional Training Council
New Bedford Area Training Committee
Fall River Area Training Committee
The Nemasket Group – Louis Nisenbaum Memorial Scholarship Fund